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Medical end-of-life decisions in Switzerland 2001 and 2013: Who is involved and how does the decision-making capacity of the patient impact?

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Abstract: **QUESTIONS UNDER STUDY:** In Switzerland, the prevalence of medical end-of-life practices had been assessed on a population level only once - in 2001 - until in 2013/14 an identical study was conducted. We aimed to compare the results of the 2001 and 2013 studies with a special focus on shared decision-making and patients' decision-making capacity. **METHODS:** Our study encompassed a 21.3% sample of deaths among residents of the German-speaking part of Switzerland aged 1 year or older. From 4998 mailed questionnaires, 3173 (63.5%) were returned. All data were weighted to adjust for age- and sex-specific differences in response rates. **RESULTS:** Cases with at least one reported end-of-life practice significantly increased from 74.5% (2001) to 82.3% (2013) of all deaths eligible for an end-of-life decision ($p < 0.001$). In 51.2% there was a combination of at least two different end-of-life decisions in one case. In relation to discussion with patients or relatives and otherwise expressed preferences of the patient, 76.5% (74.5-78.4%) of all cases with reported medical end-of-life practice in 2013 (2001: 74.4%) relied on shared decision-making, varying from 79.8% (76.5-82.7%) among not at all capable patients to 87.8% (85.0-90.2%) among fully capable patients. In contrast to a generally increasing trend, the prevalence of end-of-life practices discussed with fully capable patients decreased from 79.0% (75.3-82.3%) in 2001 to 73.2% (69.6-76.0%) in 2013 ($p = 0.037$). **CONCLUSIONS:** Despite a generally high incidence of end-of-life practices in Switzerland, there remains potential for further improvement in shared decision-making. Efforts to motivate physicians to involve patients and relatives may be a win-win situation.

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Medical end-of-life decisions in Switzerland 2001 and 2013: Who is involved and how does the decision-making capacity of the patient impact?

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Summary

QUESTIONS UNDER STUDY: In Switzerland, the prevalence of medical end-of-life practices had been assessed on a population level only once – in 2001 – until in 2013/14 an identical study was conducted. We aimed to compare the results of the 2001 and 2013 studies with a special focus on shared decision-making and patients' decision-making capacity.

METHODS: Our study encompassed a 21.3% sample of deaths among residents of the German-speaking part of Switzerland aged 1 year or older. From 4998 mailed questionnaires, 3173 (63.5%) were returned. All data were weighted to adjust for age- and sex-specific differences in response rates.

RESULTS: Cases with at least one reported end-of-life practice significantly increased from 74.5% (2001) to 82.3% (2013) of all deaths eligible for an end-of-life decision ($p < 0.001$). In 51.2% there was a combination of at least two different end-of-life decisions in one case.

In relation to discussion with patients or relatives and otherwise expressed preferences of the patient, 76.5% (74.5–78.4%) of all cases with reported medical end-of-life practice in 2013 (2001: 74.4%) relied on shared decision-making, varying from 79.8% (76.5–82.7%) among not at all capable patients to 87.8% (85.0–90.2%) among fully capable patients. In contrast to a generally increasing trend, the prevalence of end-of-life practices discussed with fully capable patients decreased from 79.0% (75.3–82.3%) in 2001 to 73.2% (69.6–76.0%) in 2013 ($p = 0.037$).

CONCLUSIONS: Despite a generally high incidence of end-of-life practices in Switzerland, there remains potential for further improvement in shared decision-making. Efforts to motivate physicians to involve patients and relatives may be a win-win situation.

Key words: alleviation of pain, assisted death, decision-making capacity, end-of-life practice, forgoing life-prolonging treatment, hastening death, patient's request, shared decision-making

Introduction

Progress in medicine has greatly increased the ability to prolong life and protract the dying process. These developments inevitably promote situations that require decision-making on medical interventions that may hasten death at the end of life, such as withholding potentially life-sustaining treatments or even administering (potentially) life-shortening drugs. Undisputedly, goals other than maximising life span have to guide medical decision-making at the end of life, especially alleviation of suffering and ensuring the best possible quality of life for the patients and support for their family members [1]. An increasingly balanced consideration of medical, ethical, psychological and societal aspects [2] supports shared decision-making: "Whenever possible, decisions on treatment and care should be made jointly by the team responsible for care of the patient and the family members" ([1], p.8).

Specific medical end-of-life decisions include: withholding or withdrawing potentially life-prolonging treatment, alleviating pain or other symptoms with drugs in doses large enough to hasten death as a possible or partly intended side effect, and physician-assisted death (prescription or supply of drugs to enable the patient to commit (assisted) suicide; administration of drugs to end the patient's life on his/her explicit request (euthanasia); ending life without the patient's explicit request [2].

Large-scale surveys to monitor medical end-of-life practices were conducted for the first time in the Netherlands in 1990/91 [3] and in Belgium in 1998 [4], accompanying the upcoming discussion on euthanasia regulation. In 2001/02 medical end-of-life practices were assessed in six European countries – the Netherlands, Belgium (Flanders), Denmark, Sweden, Italy (Emilia-Romagna, Trento, Tuscany, Veneto) and Switzerland (German-speaking part) [2]. Although prevalences were periodically assessed since then in the Netherlands and Belgium in order to monitor changes after enactment of the respective laws [5, 6], in Switzerland the 2001 survey remained was not repeated for a long time. Not before 2013/14 was an identical study conducted, with

the first key results published only very recently in a brief research letter [7].

In this paper, we aim to give a more detailed comparison of the results of the Swiss 2001 and 2013 studies. Besides prevalence figures, there is a special focus on the persons involved in decision-making and the role of the patient's decision-making capacity. There is now growing literature about patients' involvement in decision-making and shared decisions in general; however, this is mostly limited to intensive care or aggressive care settings [8, 9, 10] and therefore not generalisable to whole populations. With this study we aimed to close some of these knowledge gaps.

Methods

Death certificate survey and questionnaire 2001

In principle, the Swiss medical end-of-life decisions surveys of 2001 and 2013 had the same design and followed the structure of the 2001 EURELD survey [2]. Between September 2001 and February 2002, the Swiss Federal Statistical Office drew, in five waves, a random sample of all registered deaths of residents aged 1 year or older, occurring between June 1 and October 30, 2001. The respective death-certifying physicians received a four-page self-administered questionnaire and were asked to return it to the Swiss Academy of Medical Sciences in Basel. If the certifying physician was not the attending physician, he or she was asked to pass the questionnaire to the attending physician. Nonrespondents received at most two reminders per death case (last shipment on April 2002). In total, 4991 questionnaires were mailed, of which 3355 (67%) were returned.

The questionnaire consisted of prestructured questions derived from a common English version that was translated into the languages of the different EURELD regions and translated back into English to check for inconsistencies. Details of the questionnaire have been described elsewhere [2, 11].

Death certificate survey 2013

Between August 7, 2013 and February 5, 2014, the Swiss Federal Statistical Office drew weekly a random sample of all deaths registered for residents aged 1 year or older who had died not more than 180 days before registration. On this basis and under conditions of strict anonymity, the Epidemiology, Biostatistics and Prevention Institute of the University of Zurich (EBPI; then Institute of Social and Preventive Medicine) mailed a four-page questionnaire to the respective death-certifying physician. If the certifying physician was not the attending physician, he or she was asked to pass the questionnaire to the attending physician. Nonrespondents received at most two reminders per death case (last shipment on April 15, 2014).

The attending physicians were requested to complete the questionnaire and to return it to the Swiss Academy of Medical Sciences (SAMS; then in Basel), where the respective identifications (a four-digit number) were regularly assessed and communicated to the EBPI. SAMS only passed the filled-in questionnaires to the EBPI after the EBPI had confirmed the clearing of names and addresses of

the physicians belonging to the respective ID, ensuring that completed questionnaires could never be linked to a particular physician or patient.

Returning the questionnaire was regarded as implicit consent of the physician to participate in the study. The study was granted an official waiver for formal ethics committee review by the Zurich Cantonal Ethics Board (KEK-StV-Nr. 23/13).

In total, a 21.3% sample of deaths of residents of the German-speaking part of Switzerland was obtained and 4998 referring questionnaires were mailed. On June 11, 2014, the last completed questionnaire arrived at EBPI. In sum, 3173 questionnaires (63.5%) were returned. Questionnaires were scanned and manually completed with commentaries and notes arising from spontaneous physicians' feedback by phone or correspondence until August 2014. From September to November 2014 all hand-written commentaries and notes on the questionnaires were recorded.

The sample of deaths was 41.1% in the French- and 62.9% in the Italian-speaking parts of Switzerland (analysis in progress). Sampling fractions were derived from deaths registered in the same season of the preceding year, with the goal to reach a sample of 5000 questionnaires for the German-, 3000 for the French- and 1000 for the Italian-speaking part of the country.

Questionnaire 2013

The questionnaire was drawn up in the closest possible accordance with the 2001 survey, i.e., the international EURELD study [2] and previous death certificate studies in the Netherlands [3]. This approach was also followed in recent surveys in the Netherlands and Belgium [5, 6].

Key questions in all these studies were, whether the respective physician had:

1. Withheld or withdrawn a probably life-prolonging medical treatment taking into account or explicitly intending hastening the patient's death, or
2. Intensified the alleviation of pain and/or symptoms with drugs taking into account or partly intending hastening the patient's death.
3. Prescribed or administered a drug with the explicit intention of ending the patient's life (physician-assisted death).

For cases in which more than one end-of-life practice was reported, the most important end-of-life decision for this case was, as in previous studies [2, 3], defined as the decision with the most explicit intention concerning hastening death. If there was more than one decision with similar intention concerning hastening death, question 3 prevailed over question 2, and question 2 prevailed over question 1.

Structure

After some general questions (place of death, general practitioner or specialist, broad cause of death group, cause of death known since when, first contact with patient, "own" patient yes or no) the questionnaire asked whether the death had been sudden and unexpected. If answered negatively, the case was regarded as eligible for an end-of-life decision and the physician was asked the three key questions de-

scribed above and whether the patient had given an advance care directive, or expressed a wish to hasten death or to provide all possible life-prolonging measures. If any of the three key questions was answered positively, further information referring to the most relevant life-shortening decision was requested. In addition to an estimation of how much life was shortened and which procedures were withheld or withdrawn, the context of the decision-making process was explored, including questions whether the physician discussed the relevant end-of-life practice and, in the case of a positive answer, who initiated and who was involved in the discussion; in the case of a negative answer, the physician was asked what the reasons to abstain from discussion were. With two additional questions the ability of the patient to evaluate his or her situation and to make an adequate decision was assessed. Eventually, the physician was asked which life-prolonging treatments were applied until the end of life and whether the patient had been deeply and continuously sedated until death.

Definitions

If any of the three key questions was answered positively, cases were categorised according to the most explicit life-shortening intention into

- "forgoing life-prolonging treatment", if only key question 1 (but not key question 2 or 3) was answered positively;
- "intensified alleviation of pain and/or symptoms", if key question 2 – but not key question 3 – was answered positively;
- "physician-assisted death", comprising the following subcategories:
 - "assisted suicide", if key question 3 was answered positively and the patient him/herself administered the drug to end his/her life;
 - "euthanasia", if key question 3 was answered positively and not the patient, but somebody else administered the drug AND the question regarding the explicit request of the patient was answered in the affirmative;
 - "ending of life without the patients explicit request", if key question 3 was answered positively AND the question regarding the explicit request of the patient was NOT answered in the affirmative.

Data processing and analysis

Two rounds of plausibility checks were performed:

- Determination of valid questionnaires (e.g., two filled-in questionnaires with the same ID).
- Elimination of inconsistencies (often with consulting the original questionnaires).

All data from 2001 and 2013 were weighted to adjust for age- and sex-specific differences in response rates. In addition, data from 2001 were age-standardised to the age distribution of the 2013 study sample (this may entail slight differences from previously published figures). Final weights varied between 0.54 and 1.42 in the 2001 survey, and between 0.87 and 1.12 in the 2013 survey. Weighted percentages, 95% confidence intervals (CIs) and p-values for the comparison of 2001 and 2013 data were calculated

using the Pearson χ^2 test for two-way contingency tables (STATA 13.1 survey tables for weighted data; StataCorp LP, College Station, TX).

Results

Based on all returned questionnaires, the weighted proportion of nonsudden and expected deaths (principally eligible for an end-of-life decision) was 69.9% (95% CI 68.3–71.4%) in 2001 and 71.4% (69.8–72.9%) in 2013. Among eligible cases, the proportion of deaths preceded by at least one end-of-life practice significantly increased from 74.5% (72.7–76.3%) in 2001 to 82.3% (80.7–83.8%) in 2013 ($p < 0.001$, weighted cell counts 1747 vs 1863) (table 1). There was no consistent sex/age pattern in either the first or second survey (not shown in table). Most of the increase was due to deaths in which forgoing life-prolonging treatment was the most important decision, with 41.1% (39.1–43.2%) of eligible deaths in 2001 and 49.3% (47.3–51.4%) in 2013 ($p < 0.001$, 964 vs 1117).

In contrast to forgoing life-prolonging treatment, the percentage of deaths that were preceded by intensified alleviation of pain/symptoms as the most important end-of-life decision remained almost stable – 32.0% (30.0–33.9%) in 2001 and 29.8% (28.0–31.7%) in 2013 ($p = 0.12$, 749 vs 675) – and so did the distribution of cases where life shortening was only taken into account / was partly intended.

Physician-assisted death (assisted suicide, euthanasia or ending of life without the patient's explicit request) increased from 1.4% (1.0–1.9%) in 2001 to 3.1% (2.5–3.9%) in 2013 ($p < 0.001$, 32 vs 71).

There were a substantial number of combinations of different end-of-life decisions for one case (table 2 and fig. 1). In fact, in more of half (51.2%) of all cases eligible for an end-

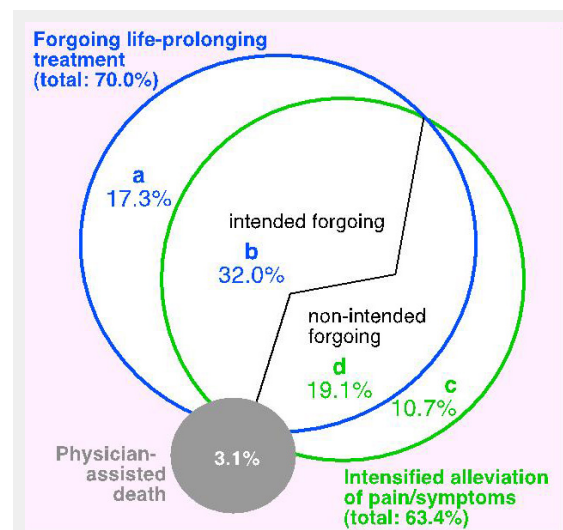


Figure 1

Overlap of different medical end-of-life practices, and categorisation as most important practice, German-speaking part of Switzerland 2013. 100% = all nonsudden expected deaths ($n = 2256$). All percentages are weighted. For categorisation as the most important end-of-life practice, (a) plus (b) were categorised as forgoing life-prolonging treatment, (c) plus (d) were categorised as intensified alleviation of pain and symptoms (see also table 2); physician-assisted death was always categorised as the most important practice.

of-life decision in 2013 there was forgoing of life-prolonging treatment AND intensified alleviation of pain/symptoms in the same case. When cases in which this was not the most important end-of-life decision were also included, the prevalence of forgoing treatment rose from 41.1% to 59.9% in 2001 and from 49.3% to 70.0% in 2013. Similarly, the total prevalence of intensified alleviation of pain/symptoms rises from 32.0% to 51.8% in 2001 and from 29.8% to 63.4% in 2013.

There is also a remarkable pattern regarding the decision-making capacity of the patient. The increase between 2001 and 2013 in the proportion of deaths preceded by at least one end-of-life practice is roughly half attributable to each of patients who were rated fully capable and patients who were not rated regarding decision-making capacity by the physician answering the questionnaire. Forgoing treatment increased and intensified alleviation decreased in all categories of capability; however, most of those lacked full capability (supplemental table S1; see appendix). In 2013, the higher the capacity of the patient, the lower the proportion of forgoing life-prolonging treatment and the higher the proportion of intensified alleviation of pain/symptoms and physician-assisted death.

Except for a slight shift from healthcare professionals to other physicians, the proportions of involved persons in 2013 were almost identical to those in 2001 (table 3), with either patient or relatives involved in 72.2% (70.1–74.2%) of all deaths with mention of an end-of-life practice (2001: 70.3%, 68.0–72.4, $p = 0.22$, 1227 vs 1345).

In 2013, end-of-life issues were discussed with the patient in 35.6% (33.4–37.8%) of all deaths with at least one reported medical end-of-life practice. Prevalence of involvement is strongly dependent on the patient's decision-mak-

ing capacity: end-of-life issues were discussed in 2013 with 73% of the fully capable patients, but only with 37% of the not fully capable and 10% of the not at all capable patients (table 4). Generally, there is a tendency to increased involvement of patients, with, nevertheless, one striking exception: among patients with full capacity, the prevalence of end-of-life practices discussed with the patient decreased from 79.0% (75.3–82.3%) in 2001 to 73.2% (69.6–76.0%) in 2013 ($p = 0.037$, 432 vs 459).

When discussion with relatives and otherwise expressed preferences of the patient were also taken into account, 76.5% (74.5–78.4%) of all cases with reported medical end-of-life practice in 2013 relied on shared decision-making, varying from 79.8% (76.5–82.7%) among the not at all capable patients to 87.8% (85.0–90.2%) among fully capable patients. Whereas for the former this implies a significant increase compared with 2001 (72.7%, $p < 0.003$, 487 vs 517), there is still a slight but insignificant decrease for the latter (2001: 89.1%, $p = 0.51$, 487 vs 550).

Discussion

In the German-speaking part of Switzerland in 2013, more than four of five nonsudden deaths were preceded by at least one end-of-life practice. The prevalence of deaths with at least one reported end-of-life practice significantly increased from 52.0% of all deaths in 2001 to 58.7% in 2013 [7], from 74.5% to 82.3%, respectively, of all deaths eligible for an end-of-life practice. This increase is in line with trends in the Netherlands (43.8% of all deaths in 2001 and 57.8% in 2010)[5] and in Belgium (38.4% in 2001 and 47.8% in 2013)[6].

Table 1: Prevalence of medical end-of-life practices* in the German-speaking part of Switzerland, 2001 vs 2013 (100% = all non-sudden expected deaths; percentages weighted and standardized to 2013 deaths).

* If more than one end-of-life practice was reported, the most explicit regarding life-shortening was decisive for classification.

Nonsudden expected deaths (eligible for end-of-life decision)	2001 (n = 2281)	2013 (n = 2256)	Trend
	Percentage (95% CI)	Percentage (95% CI)	p-value (weighted cell counts 2001, 2013)
No end-of-life practice	25.5% (23.7–27.4)	17.7% (16.2–19.3)	<0.001 (598.4, 400.8)
With end-of-life practice	74.5% (72.7–76.3)	82.3% (80.7–83.8)	<0.001 (1746, 1863)
Forgoing life-prolonging treatment	41.1% (39.1–43.2)	49.3% (47.3–51.4)	<0.001 (964.4, 1117)
Taking into account hastening of death ¹	10.5% (9.3–11.9)	6.4% (5.4–7.5)	<0.001 (246.5, 144.2)
Intending hastening of death ²	30.6% (28.7–32.6)	43.0% (40.9–45.0)	<0.001 (717.9, 973.1)
Intensified alleviation of pain/symptoms	32.0% (30.0–33.9)	29.8% (28.0–31.7)	0.121 (749.3, 675.1)
Taking into account hastening of death ³	28.4% (26.5–30.3)	26.9% (25.1–28.8)	0.270 (664.9, 608.6)
Partly intending hastening of death ⁴	3.6% (2.9–4.5)	2.9% (2.3–3.7)	0.207 (84.5, 66.5)
Physician-assisted death	1.4% (1.0–1.9)	3.1% (2.5–3.9)	<0.001 (32.4, 70.9)
Assisted suicide ⁵	0.4% (0.2–0.7)	1.6% (1.1–2.2)	<0.001 (9.7, 35.3)
Euthanasia ⁶	0.3% (0.2–0.7)	0.5% (0.3–0.8)	0.438 (7.7, 10.6)
Ending of life without the patient's explicit request ⁷	0.6% (0.4–1.1)	1.1% (0.7–1.6)	0.095 (15.0, 25.0)

¹ Affirmative answer to the question, "Did you or another physician withhold or withdraw a medical treatment while taking into account the possible hastening of death?"

² Affirmative answer to the question, "Did you or another physician withhold or withdraw a medical treatment with the intention to hasten death?"

³ Affirmative answer to the question, "Did you or another physician intensify the alleviation of pain and/or symptoms while taking into account the possible hastening of death?"

⁴ Affirmative answer to the question, "Did you or another physician intensify the alleviation of pain and/or symptoms partly with the intention to hasten death?"

⁵ Affirmative answer to the question, "Was death the consequence of the use of a drug that was prescribed or supplied by you or another physician with the explicit intention of enabling the patient to end his or her life?"

⁶ Affirmative answer to the question, "Was death the consequence of the use of a drug that was prescribed or supplied by you or another physician with the explicit intention of hastening the patient's death?" AND affirmative answer to the question: "Was this decision made at the explicit request of the patient?"

⁷ Affirmative answer to the question, "Was death the consequence of the use of a drug that was prescribed or supplied by you or another physician with the explicit intention of hastening the patient's death?" AND no affirmative answer to the question: "Was this decision made at the explicit request of the patient?"

In Switzerland, most of this increase is due to forgoing life-prolonging treatment as the most important end-of-life decision. The prevalence of this practice was already in 2001 one of the highest in Europe [2] and the increase since then contrasts to the situation in other countries, where only a modest increase (Belgium, [6]) or even a slight decrease (the Netherlands, [5]) was observed.

The prevalence of intensified alleviation of pain/symptoms as the most important end-of-life decision in relation to all deaths was in 2001 similar to that in Belgium and the Netherlands [2], and in relation to all deaths with end-of-life decisions was even clearly lower. The slight decrease between 2001 and 2013 is at variance with an increase in

Belgium [6] and an even more pronounced increase in the Netherlands [5].

However, the in-depth analysis presented in this paper revealed that in fact there was in Switzerland also an increase of intensified alleviation of pain/symptoms in this period. This increase does not become obvious in a unidimensional categorisation according to the most important end-of-life decision, as Swiss physicians in 2013 much more often than in 2001 attributed an intention of hastening death to their decision to forgo life-prolonging treatment, meaning that those “intended forgoing treatment decisions” very often overruled an intensified alleviation of pain/symptoms. This seems to point to an increasingly complex interweaving of different end-of-life decisions in modern medical

Table 2: Forgoing life-prolonging treatment and intensified alleviation of pain and symptoms, German-speaking part of Switzerland 2001 vs 2013 (100% = all nonsudden expected deaths; percentages weighted and standardized to 2013 deaths).

Nonsudden expected deaths (eligible for end-of-life decision)	2001 n = 2281	2013 n = 2256	Trend
	Percentage (95% CI)	Percentage (95% CI)	p-value (weighted cell counts 2001, 2013)
Forgoing life-prolonging treatment			
Total	59.9% (57.8–61.9)	70.0% (68.1–71.9)	<0.001 (1403, 1585)
Life-shortening accepted	28.6% (26.8–30.6)	25.8% (24.0–27.6)	0.033 (671.1, 583.7)
Life-shortening intended	31.2% (29.3–33.2)	44.2% (42.2–46.3)	<0.001 (732, 1001)
Not combined with other medical end-of-life practice (a)	22.4% (20.7–24.2)	17.3% (15.8–18.9)	<0.001 (525, 392.1)
Combined with intensified alleviation of pain/symptoms only	36.6% (34.6–38.7)	51.2% (49.1–53.2)	<0.001 (858.6, 1158)
- Ditto, only intended forgoing of treatment (b)	18.7% (17.2–20.4)	32.0% (30.1–34.0)	<0.001 (439.4, 725.2)
Combined with physician-assisted death	0.8% (0.5–1.3)	1.5% (1.1–2.1)	0.030 (19.5, 34.6)
Intensified alleviation of pain/symptoms			
Total	51.8% (49.7–53.8)	63.4% (56.0–58.9)	<0.001 (1213, 1435)
Life shortening accepted	41.1% (39.1–43.2)	51.7% (49.7–53.8)	<0.001 (963.8, 1172)
Life-shortening partly intended	10.6% (9.4–12.0)	11.6% (10.5–13.0)	0.294 (249.5, 263.3)
Not combined with other medical end-of-life practice (c)	14.1% (12.7–15.6)	10.7% (9.5–12.0)	<0.001 (330.1, 241.9)
Combined with forgoing life-prolonging treatment only	36.6% (34.6–38.7)	51.2% (49.1–53.2)	<0.001 (858.6, 1158)
- Ditto, only unintended forgoing of treatment (d)	17.9% (16.3–19.5)	19.1% (17.6–20.8)	0.281 (419.2, 433.2)
Combined with physician-assisted death	1.0% (0.7–1.6)	1.5% (1.0–1.7)	0.150 (24.5, 34.5)
Forgoing life-prolonging treatment as most explicit end-of-life decision (cf. table 1): (a) + (b)			
Intensified alleviation of pain/symptoms as most explicit end-of-life decision (cf. table 1): (c) + (d) (see also fig. 1)			

Table 3: Persons involved in medical end-of-life decisions, German-speaking part of Switzerland 2001 vs 2013 (multiple answers allowed). (100% = all deaths with reported end-of-life practice; percentages weighted and standardised to 2013 deaths).

Deaths with end-of-life practice mentioned (eligible for involvement)	2001 n = 1704	2013 n = 1856	Trend
	Percentage (95% CI)	Percentage (95% CI)	p-value (weighted cell counts 2001, 2013)
No information about involved persons ¹	6.3% (5.2–7.5)	10.3% (9.0–11.8)	<0.001 (109.1, 192)
Not discussed ²	10.9% (9.4–12.5)	7.5% (6.4–8.8)	<0.001 (190.8, 140.2)
Discussion with patient ³	34.1% (31.9–36.4)	35.6% (33.4–37.8)	<0.001 (595.6, 662.9)
Relatives involved ⁴	64.5% (62.2–66.8)	66.1% (63.9–68.2)	<0.001 (1127, 1231)
Patient or relatives involved	70.3% (68.0–72.4)	72.2% (70.1–74.2)	0.218 (1227, 1345)
Patient and relatives involved	28.4% (26.3–30.6)	29.5% (27.4–31.6)	0.466 (495.4, 549.5)
Other physician(s) involved ⁵	35.4% (33.2–37.7)	48.0% (45.7–50.3)	<0.001 (618.4, 894.1)
Healthcare professionals involved ⁶	51.6% (49.2–54.1)	41.4% (39.2–43.7)	<0.001 (901.9, 772.4)
Other person(s) involved ⁷	4.4% (3.5–5.5)	2.1% (1.6–2.9)	<0.001 (76.3, 39.7)

¹ None of the two respective questions answered

² Both respective questions answered with “no”

³ Affirmative answer to the question, “Did you or another physician discuss the end-of-life practice and the potential hastening of death with the patient?”

⁴ Affirmative answer to the question, “Did you or another physician discuss the end-of-life practice and the potential hastening of death with one or more relatives of the patient?”

⁵ Affirmative answer to the question, “Did you or another physician discuss the end-of-life practice and the potential hastening of death with one or more physicians?”

⁶ Affirmative answer to the question, “Did you or another physician discuss the end-of-life practice and the potential hastening of death with one or more health care professionals?”

⁷ Affirmative answer to the question, “Did you or another physician discuss the end-of-life practice and the potential hastening of death with somebody else?”

end-of-life practice, making it more difficult to attach a particular end-of-life decision as the most important one to a specific patient.

In our 2013 study, only a small minority of end-of-life decisions were not discussed by the involved physician (8.4%, if missing answers on the respective questions were rated as random failure and 17.8% if they were defined as "not discussed"). In the 2001 survey (German) Switzerland already scored well in this respect [2] and between the two surveys involvement of patients even increased, but rather modestly in view of the increase in health literacy and the paradigmatic change from paternalistic to shared decision-making that occurred in the past decades [12, 13].

Excluding records with unknown patient's capacity, in at least 80% of cases medical end-of-life discussions in 2013, the patient him/herself or his/her relatives were involved or the patient's preferences were already known to the physician, with only modest variation between categories of patient's decision-making capacity.

Within a general tendency to increasing shared decision-making between 2001 and 2013, the decreased incidence of discussion with fully capable patients from 79.0% to 73.2% (borderline significance) is striking. Including all kinds of patient's involvement (relatives, otherwise known preferences), the decrease (89.1% vs 87.8%) is insignificant.

Nevertheless, one might ask why not all fully capable patients were involved in decision-making. Comparing fully capable patients with and without involvement revealed only a few differences. "Obviously in the interest of the patient" as reason for not having discussed decision-making was mentioned in 2013 for three out of ten cases with no discussion. However, this answer was even more frequent in 2001. A more remarkable difference concerns the type of most important end-of-life procedure, since the proportions forgoing a treatment and intensified alleviation of pain/symptoms were exactly inverted among those with no involvement (2013: 33.4% forgoing treatment vs 65.2% alleviation). One might assume that this is due to a different distribution according to causes of death, with cancer patients needing more alleviation. However, the respective variation is far too small to explain the described difference. One might, therefore, speculate that forgoing treatment was rated by capable patients as more relevant than intensified alleviation and that the latter was understood as pal-

liative or even comfort therapy in order to increase quality of life and, therefore, not equally important to be discussed. Another explanation may be that end-of-life decision discussions are demanding and there are many obstacles to a good conversation, especially indisposition of the physician or unwillingness of the patient or the family to consider the approach of death [14].

The relatively high proportion with intensified alleviation of pain/symptoms among fully capable patients might be due to a better ability among these patients to describe their symptoms and to draw upon customised treatment schemes, e.g. for pain, dyspnoea, nausea or restlessness. Another reason may be cancer patients: they are younger and more prevalent among the fully capable, and generally they often need alleviation of pain [15].

It also cannot be ruled out that in some cases end-of-life discussion was planned, but outpaced by death or unexpected loss of decision-making capacity. Unfortunately these issues were not included in the predefined answers to the question about reasons for forgoing discussion with the patient. Findings of an Australian study, where 77% of inpatients had their first documented end-of-life discussion only 3 days before death [16], as well as of a Dutch study, where the proportion of people with limited decision-making capacity increased from 27% 1 month before death to 67% in the last week of life [17] support the notion that discussion could be missed more often than might be expected.

Strengths and limitations

Given the voluntary nature of the survey, independent of reporting duties or changing legislative background, the response rates (63.5% in 2013, 67.2% in 2001) in German-speaking Switzerland are remarkably high and only slightly lower than in the Netherlands (75% in 2001 [2], 74% in 2010 [5]). The substantial sample of deaths can, therefore, be seen as representative for all deaths in all settings in German-speaking Switzerland, allowing valid comparisons between 2001 and 2013. Although the optimal phrasing of the questionnaire is the subject of a continuing controversy [18, 19], it is widely accepted that this kind of study is still the gold standard for assessing medical end-of-life decisions on a population level.

Table 4: Discussion of medical end-of-life decisions in function of the patient's decision-making capacity, German-speaking part of Switzerland 2001 vs 2013. (100% = all deaths with reported end-of-life practice; percentages weighted and standardized to 2013 deaths).

Deaths with end-of-life practice mentioned (eligible for involvement)	2001 n = 1704	2013 n = 1856	Trend
	Percentage (95% CI)	Percentage (95% CI)	p-value (weighted cell counts 2001, 2013)
Discussed with patient ³	34.1% (31.9–36.4)	35.6% (33.4–37.8)	<0.001 (595.6, 662.9)
Patient fully capable	79.0% (75.3–82.3)	73.2% (69.6–76.0)	0.037 (432.1, 458.7)
Patient not fully capable	32.4% (27.7–37.6)	37.1% (32.2–42.3)	0.196 (116.9, 133.7)
Patient not capable at all	6.7% (5.0–8.9)	9.7% (7.6–12.2)	0.051 (44.71, 62.77)
Patient's capability unknown	1.2% (0.3–4.5)	3.4% (0.2–6.7)	<0.001 (1.94, 7.75)
Discussed with patient and/or relatives and/or patient ever expressed wish	74.4% (72.2–76.5)	76.5% (74.5–78.4)	0.138 (1297, 1425)
Patient fully capable	89.1% (86.1–91.5)	87.8% (85.0–90.2)	0.508 (487.2, 550)
Patient not fully capable	80.1% (75.5–84.0)	85.3% (81.2–88.6)	0.073 (288.6, 307)
Patient not capable at all	72.7% (69.0–76.1)	79.8% (76.5–82.7)	0.003 (486.8, 517.3)
Patient's capability unknown	21.6% (15.8–28.9)	22.1% (17.2–28.0)	0.910 (36.6, 50.6)

This study has several limitations. All information is derived from physicians' reports, and is thus dependent on the physicians' assessment of the situation – which is, however, most appropriate for the physician's intention and therefore medical end-of-life practices. However, we do not know the contents and outcome of the discussions between physicians and patients, relatives and other caregivers, a knowledge relevant to developing standards [4]. We also cannot exclude the possibility of a nonresponse bias, all the more as an affirmative answer to question 6 "Was death sudden and unexpected" offered an easy option to skip all potentially sensitive questions. While we cannot test this, we found indications supporting the finding of Fischer et al. that in the 2001 survey nonresponders had significantly fewer terminal patients than responders [20]: among cancer patients, who make up a stratum with higher likelihood of an end-of-life decision, in our study response was also higher. This probably also applies to the responding physicians' personal interest in and attitudes towards end-of-life issues. As a consequence, prevalence rates might be overestimated, but should not bias either the relative differences between subgroups or the comparison of 2001 and 2013.

Conclusion

In our Swiss study population, incidence of end-of-life decisions in general and of shared decision-making in particular was remarkably high. There was increasingly a variety of different end-of-life practices interweaved in one patient. A deeper understanding of the frequency of medical end-of-life decisions requires analysis of this pattern, e.g., including combinations, rather than just focussing on the construction of a "most important end-of-life decision" in a particular case.

In general, there is a high level of involvement of patients and relatives in the decision-making process. Nevertheless there remains potential for improvement, since cases without intelligible explanation for missing discussion still do not seem to be rare exceptions. It may, therefore, be useful to analyse social disparities, for example educational level, which have been shown to entail an unequal use of palliative care [21].

It is also known that among physicians there still exist obstacles to addressing end-of-life issues [14]. More sustained efforts to increase motivation may, therefore, be indicated in order to increase certainty of optimal decisions and the satisfaction of relatives [8].

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Appendix

Supplementary table

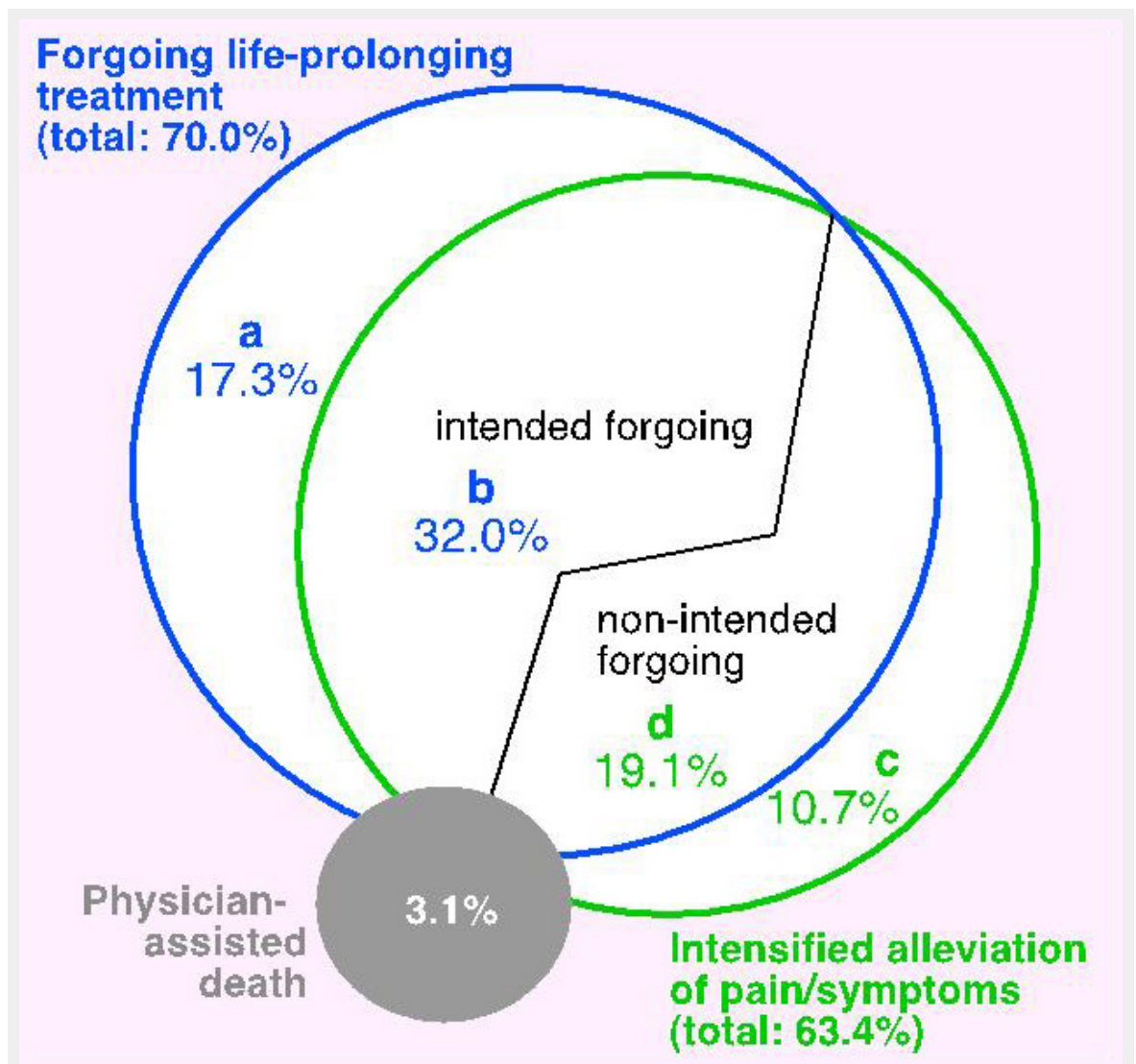
Table S1: Medical end-of-life decisions* by level of patient's decision-making capacity, German-speaking part of Switzerland 2001 vs 2013. (100% = all deaths with reported end-of-life practice; percentages weighted and standardized to 2013 deaths).

* If more than one end-of-life practice was reported, the most explicit regarding life-shortening was decisive for classification.

Deaths with end-of-life practice mentioned (eligible for involvement)	2001 n = 1704	2013 n = 1856	Trend
	Percentage (95% CI)	Percentage (95% CI)	p-value (weighted cell counts 2001, 2013)
Patient rated as fully capable	n = 548 (100%)	n = 625 (100%)	
Forgoing life-prolonging treatment	53.8% (49.6–58.1)	59.4% (55.4–63.1)	0.060 (294.4, 371.7)
Intensified alleviation of pain/symptoms	42.6% (38.4–46.8)	36.4% (32.7–40.3)	0.034 (232.9, 228.3)
Physician-assisted death	3.6% (2.3–5.5)	4.2% (2.9–6.1)	0.579 (19.6, 26.3)
Patient rated as not fully capable	n = 348 (100%)	n = 357 (100%)	
Forgoing life-prolonging treatment	51.6% (46.3–56.9)	62.0% (56.8–66.9)	0.006 (186, 223.1)
Intensified alleviation of pain/symptoms	47.3% (42.0–52.6)	35.8% (31.0–40.9)	0.002 (170.3, 128.8)
Physician-assisted death	1.1% (0.5–2.8)	2.2% (1.1–4.4)	0.231 (4.1, 8.1)
Patient rated as not at all capable	n = 641 (100%)	n = 644 (100%)	
Forgoing life-prolonging treatment	65.3% (61.5–69.0)	69.9% (66.6–73.3)	0.083 (437.4, 453.3)
Intensified alleviation of pain/symptoms	34.2% (30.5–38.0)	28.5% (25.2–32.2)	0.032 (228.7, 185.1)
Physician-assisted death	0.5% (0.2–1.6)	1.6% (0.8–2.9)	0.078 (3.5, 10.1)
Patient's capability not rated ¹	n = 167 (100%)	n = 230 (100%)	
Forgoing life-prolonging treatment	27.5% (21.0–35.0)	30.3% (24.6–36.6)	0.558 (46.5, 69.2)
Intensified alleviation of pain/symptoms	69.4% (61.8–76.1)	58.2% (51.6–64.4)	0.025 (117.5, 133)
Physician-assisted death	3.1% (1.4–6.8)	11.6% (8.0–16.4)	0.001 (5.2, 26.5)

¹ Neither of the two respective questions answered

Figures (large format)

**Figure 1**

Overlap of different medical end-of-life practices, and categorisation as most important practice, German-speaking part of Switzerland 2013. 100% = all nonsudden expected deaths (n = 2256). All percentages are weighted. For categorisation as the most important end-of-life practice, (a) plus (b) were categorised as forgoing life-prolonging treatment, (c) plus (d) were categorised as intensified alleviation of pain and symptoms (see also table 2); physician-assisted death was always categorised as the most important practice.